The Birkbeck Pain Project

PAIN AND ITS MEANINGS

Supported by Wellcome Trust
Introduction

This thing called ‘pain’ does not emerge naturally from physiological processes, but in negotiation with social worlds. From the moment of birth, infants are initiated into cultures of pain. Some infants are dragged from the womb with forceps. Many have their buttocks slapped to force that first raw breath. As the infant matures, those people responsible for its socialisation pay attention to some tears, and not others. Hands are smacked as they reach for flames. Some cuts are kissed better; some bruises, overlooked. It makes a difference if you are a boy. It matters if you are poor. People in pain learn how to ‘suffer silently’ or ‘kick up a fuss’. Scraped knees, toothaches, giving birth, cancer, heart attacks, and heartaches: pain permeates our entire lives. Yet, it also seems to be a mystery.
Two years ago I decided to make my own inchoate encounters with pain more tangible. Thanks to generous funding from the Wellcome Trust, I formed the Birkbeck Pain Project with Dr Carmen Mangion (a specialist on religious suffering) and Dr Louise Hide (who focuses on pain in mental institutions). We set out to explore the various ways people in Anglo-American societies from the eighteenth century to the present have sought to communicate their agony – to themselves as well as to their loved ones, clinicians, and others. We immersed ourselves in diaries, letters, memoirs, medical journals, casebooks, oral histories, and newspapers – paying particular attention to accounts written by the dispossessed, minorities, and the poor.

We begin from the premise that pain is not an object; it is a type of event. Crucially, pain is not an intrinsic quality of raw sensation; it is a way of perceiving an experience. Pains are modes of perceptions: they are not the injury or noxious stimuli itself but the way we evaluate the injury or stimuli. Pain is a way of being-in-the-world and, as such, is far from static or monochrome, which is why it requires a history. Pain events are unstable; they are historically constituted and reconstituted in relation to three processes: language systems, social and environmental interactions, and bodily comportment. Our historical question is: how has pain been done in the past and what ideological work do acts of being-in-pain seek to achieve? By what mechanisms do these types of event change?

Because we believe we can better understand pain, not through illness and disease categories but through an appreciation of the body-in-pain, we have spent a great deal of time analysing the languages used by pain-sufferers. Although communicating states of pain might pose particular difficulties for sufferers, the languages that people seize hold of in order to overcome some of those obstacles tell us a great deal about their experiences. By listening to the ways people communicate their pain, we can uncover clues to complex, unspoken meanings. An actively stabbing knife (‘it felt like someone was stabbing me’) says something different from a description of pain as a colour (‘a well of red, flowing anguish overtook me’). Metaphors of submission (say, to the will of God) convey a different rapport with one’s pain than metaphors of resistance (as in attempting to conquer the pain-inducing invader). By tracing how these metaphors and languages differ between cultural groups, environmental situations, and over time, we can access the history of sensation.
As part of our project, we hosted a public event at Wellcome Collection called ‘Pain and its Meanings’. As well as presenting a series of talks from leading thinkers across academic and creative disciplines, we screened a short film by artist Deborah Padfield and premiered two specially-commissioned artistic works: a short drama set to music by Daniel Eisner Harle and a poem by prize-winning poet, Jo Shapcott. In the following pages, Deborah Padfield explains the genesis of her film, we publish Jo Shapcott’s poem ‘P’ in full, together with the libretto and first section of the score for As Above, So Below by Daniel Eisner Harle.

The Birkbeck Pain Project has been an illuminating journey. We hope that ‘Pain and Its Meanings’ can continue to offer new insights into this thing called pain.

10 December 2012
1. Contract

Please, not the one
a dog would be put down for;

and let it not be the one
which is chronic;

nor the one
which is acute;

let it not be the one
to demand its own journal;

not the one
between seven and ten, or at ninety percent;

not the one
I can point to with my finger;

Jo Shapcott

Healing the sick, fresco by Domenico di Bartolo, Sala del Pellegrinaio (hall of the pilgrim), Hospital Santa Maria della Scala, Siena. © Jastrow, 2005.

Jo Shapcott is an award-winning poet. Work from her collections Electroplating the Baby (1988), Phrase Book (1992) and My Life Asleep (1998) are gathered in Her Book: Poems 1988-98 (2000). She has won the Commonwealth Writers' Prize, the Forward Prize and the National Poetry Competition (twice). Tender Taxes, her versions of Rilke, was published in 2001. Her most recent collection, Of Mutability, won the Costa Book of the Year Award and the Queen's Gold Medal for Poetry. She teaches at Royal Holloway, University of London.
and, even more, not the one
I can't point to;
not the one
I am asked to describe as black, or red, or; is it, white;
not the one
with my own button to press, but not too often;
not the one
which is postmodern;
not the one
which is a needle, a hive, an iceberg, a volcano;
not the one
high on heartbeat, skin conductance and EEG;
not the one
which is classic;
not the one
which is earth, which is air, which is fire, which is water;
let it not be the one
where all the words and numbers live;
not the one
with my face.

2. Inheritance
The first body drew
a safe, nerve-coat round itself,
called it p . . . , p . . . , p . . .

3. Promise
One day, I promised my body
this was IT: I would stay,
put up with its little aches
and trickles, twitches, gurgles
and clicks. The noisy thing,
it would be clean, well-fed.
I would buff its nails, part
its hair and keep it covered
in public with soft fabrics:
fluffy cottons, velvets, lambswool.
Then my body opened its mouth,
shouted, actually, said things I can't
say; then, after long silence,
swallowed me whole.
So now I am my body, nothing
less, and this is me, speaking.
4. Task

It isn't hard, 
the job of breathing.

Ah

It’s not even hard 
to speak of breathing

Ah

and the insects and whirlers 
inside and all their

Ah

spiky complicity 
in the day to day.

Ah

5. Gift

You take the red box, 
pull ribbons which fall in waves, 
and are not grateful.

6. Ornament

Here is a decoration living inside, let's say, 
the abdomen, 
a place already – as surgeons know – crammed with 
ochres, reds, creams

and all the beige/browns – but only

darkness
to the tender one who is the body and so

can't just reach in
to test what might be lost when 
the sparkler

is lifted out, too bright for words.

7. Mistake

Not why, not why, not why, not why, not why –

Why not, why not, why not, why not, why not –

Me
8. Dream

I have seen a man
in a renaissance fresco
with a gash in his leg
to the bone.
The artist has given
the frilly skin and muscle tears
in the split thigh – the creamy femur –
his best attention.

The man is looking up, away from his wound,
at the ceiling (ornate),
or at the crowd of doctors in black hats
who gaze down at him, envious of one
who dares to wear on the surface
a beauty more usually tucked inside.

© Jo Shapcott. Commissioned by the Birkbeck Pain Project, funded by the Wellcome Trust.

Deborah Padfield

*duet for pain*

**duet for pain** is a short film made during an artist’s residency at University College London Hospitals (UCLH) exploring a space between medical and fine art research. It collages the voice of a pain sufferer and former model, with that of a pain specialist to construct a dialogue between different perspectives.

Re-filming and re-projecting its subjects within medical and photographic frameworks, the film aims to question the impact of both facial pain and photographic portraiture on the construction of role and identity, emphasizing the relevance of narrative to clinical pain encounters. Here, Deborah Padfield discusses with Louise Hide how her creative, intellectual and personal journeys intersected before and during the making of the film.
What initiated your interest in pain and laid the foundations for the film project?

My own experience of chronic pain, of living with it, and trying to understand it better. This led to a project at St Thomas’s Hospital where I worked with patients to create photographic still images to make their experiences of pain more tangible. I was interested in the invisibility of pain, and the differences between what a sufferer experiences subjectively and what onlookers observe objectively. When the schism between the two grows wider, communication becomes distorted and life becomes more difficult to navigate. I wanted to explore how these images could be used to improve doctor/patient communication in the consulting room. The project led to a touring exhibition, a book *Perceptions of Pain* and ongoing research.

That research is being developed further in a new collaboration with Professor Joanna Zakrzewska, a consultant in facial pain at UCLH. The new project, *face2face*, has several strands. One was a series of art workshops for clinicians and patients. Another was the co-creation of photographic images with facial pain patients, aiming to reflect their individual experience of pain. Together, we explored how their experiences of facial pain could inform photographic portraiture, asking what the photograph reveals about facial pain. What is the effect of the lens? Are there parallels between the exchanges within photographic portraiture and doctor/patient dialogue? We worked with patients before, during and after their treatment to create images that reflected changes they made in their perception of pain, aware that we may have also contributed to those changes.

How did duet for pain emerge from this work?

Following on from my initial interest in visual pain – making it more real, credible and tangible through photographs – I became increasingly absorbed in communication either between clinicians and patients, myself and patients, or myself and clinicians. It is a constant process of negotiation: they bring their aesthetic, I bring my aesthetic. People come up with creative metaphors that are unique and bizarre on the one hand, but totally apt and appropriate on the other. They bring their incredibly intense experience to the process and, while I want to do justice to it, there are still things I want to try out visually. So we try together to get something that can communicate their experience to people outside our relationship. When those images are taken to family members or into a clinical consultation the narrative gets reconstructed again. I think the film brings out the importance of narrative and its value in pain consultations.

Did you bring a different creative process to the film?

The images I make with pain sufferers are very much a co-creative process. When making the film, I gave myself the licence to author it. Both participants – Francine, the pain sufferer and Joanna Zakrzewska, the clinician – were very
trusting. I felt I could shift things around to create a surreal and almost disorientating environment to capture something of the different languages and rhythms of speech. Joanna is very precise, very clear about pain and its management. She is very empathetic, presenting a professional role in professional language. Francine is very lyrical, very personal. Her language is emotive, containing many pauses, and quite reflective. So the presentation of pain is very different, even though the two are co-existing alongside each other.

How is your own experience reflected in the film?

Before I was an artist, I trained as an actor when I learned to use my body to communicate. When I had chronic pain following surgery, I couldn’t use my body in that way any more. In hospital, I started drawing in order to process what was happening to me. I realised that externalising this stuff in some way was helpful because it was no longer locked in and hidden and trapped, or in a knot that you can’t find your way through. Through drawing and discussing the drawings with my GP, I could externalise pain, untangle it a little bit.

It’s important to feel you have some control over your pain. For pain sufferers, it’s about not losing control over your identity and how it’s presented or constructed. I find this particularly interesting in the clinical encounter, because there is a sort of performance going on. Who is in control? The person in pain or the clinician? The pain sufferer may take control and go into a very long story, reiterating it time and again, so it becomes crystalised through the telling. The clinician may take control by going through a set of standard questions. So how can you effect a shift in dialogue to create a meaningful exchange – in that room, at that moment?

It has something to do with the construction of the narrative, triggered by images and what is happening during the dialogue as the pain encounter is taking place. Francine says ‘the body is not important’, implying it is all in the face, perhaps because she
was a professional model. But if your face is in intense pain, it can’t express it in the way that it would if your knee or your arm were in pain. In many cases, for example with trigeminal neuralgia, the face freezes with pain. This means there is a disconnect between what other people are perceiving or interpreting, and what that person is feeling behind the face. People with facial pain are very aware of this, but these kinds of disconnects happen to all of us all the time.

Describe your aesthetic approach to the film

The first time I filmed Francine, I projected her image into a photographic tray filled with moving water. I always find watching an image appear in a developing tray quite magical. In the same way, I loved watching her face reflected and changing in the water; there was something very luminous about it, quite ethereal. This was also a reference to her professional life: she knows how to use a camera more than anyone I have interviewed. She was completely at ease presenting herself through the lens. I chose to project the film of Joanna’s interview onto the light box, so you have almost a disembodied voice of the medical establishment through an imaging device. I then re-projected and re-filmed the footage splicing both interviews together. I was deconstructing and reconstructing a narrative that appears linear on one level, but underneath touches that very surreal nature of pain. Wrapped around this is the uncanniness, the eeriness of the clinical environment that I think is part of that professional construction, but also very disorientating and in some senses disempowering, although Joanna does try to humanise the room. There are so many dualities – outside and inside the body, outside and inside the room, outside and inside the building, outside and inside the medical framework.

What kind of ethical considerations have you faced?

Everyone I have photographed or filmed has agreed for these images to be shown in a public space. If there were times during the co-created photographs when the participant and I wanted to do something aesthetically different, I might draw back. With the film I allowed myself to make the aesthetic decisions. Maybe I felt slightly less ethical when making the film because you are spending hours and hours editing someone’s face, someone’s language and the more you are disconnecting from the initial film process, the more you are constructing and reconstructing another’s identity. I felt less comfortable with that, but it did give me more creative freedom.

How do people respond to the film?

Usually there is an awkward silence at the end because we have been watching someone’s very real suffering. Pain is treated by society very differently from illnesses that are more tangible and easier to explain. For me, the world is surreal and bizarre, as is pain, so I can quite easily inhabit
this world. Pain reveals a lot about being human, about humanity, our tolerance and ability to accept each other’s experiences.

Initially, I was worried about the film being too bleak. But there is poetry in Francine’s way of understanding and managing her pain. Many people tend to stay away from witnessing that level of suffering. It can be difficult to hear, difficult to see. But it needs to be acknowledged. I think the film works because there is a reality and an intensity to it. Ultimately, you are left with someone who has been generous enough and brave enough to put their very real suffering into a very public space.
A short drama in two parts

Music by Daniel Eisner Harle
Words by Spencer Noble

Cast:
Mr. Clarke: Nick Allen
Miss Sinclair: Rosie Lomas

Band:
Hurdy Gurdy: Steven Tyler
Flugal horn/trumpet: Darren Moore
Flutes: Rosanna Terberg
As Above, So Below is a short drama in two parts, set to music. Miss Sinclair goes to Mr. Clarke for advice on her illness. Mr. Clarke initially dazzles her with his seemingly limitless knowledge but after five weeks of following his orders to no avail, Miss Sinclair’s confidence in Mr. Clarke is tested.

**Part One: Diagnosis**

Mr. Clarke: Miss Sinclair I received your Letter

Miss Sinclair: My letter, ah yes my letter...

MC: Yes ... Please sit down Miss... Sinclair... (diverting subject) How do you feel?

MS: Well it started, it’s nothing.

MC: Nothing... a fever?

MS: Fever, I have fever... so nauseous, it’s nothing.

MC: Nothing... a rash?

MS: A rash, on my neck! See my neck!

MC: (looks at neck) I see your neck, your food?

MS: Organic, rye, veg, fish, local produce, Zinc supplements for my skin, my youth would...

MC: (irritated) Black hats, black cats, black clothes, don’t confide in these ‘wise women’.

MS: Excuse me?

MC: I mean try not to self-diagnose - the rash, apt cause, be proteins...

MS: Proteins...

MC: Owing to your new diet, seeds and nuts must be avoided.

MS: And the supplements?
MC: All prescriptions must be signed, that is the doctrine, walnuts are good for the head, because walnuts look like a head.

MS: (outpouring, slightly exasperated) I need you to listen; my youth would despise me, my job it hurts me, my rash...

MC: (offering hasty advice) Tenacious faith ceased the pain of job.

MS: Such sensitive intelligence! I ache...

MC: (interrupting) One problem per appointment please, complaint is the mind’s placebo, stiff upper lip or analyst, I’ve no medicine for ego.

MS: But my rash? My fever?

MC: You display symptoms of Ergotism.

MS: Ergotism?

MC: Swelling and pain embroiling, pimples, fevers, black bile rolling...

MS: It’s true, I work so hard.

MC: Blisters popping, wimples soiling...

MS: No time to be single.

MC: You have St. Anthony’s fire, it’s really nothing.

MS: Nothing?!

MC: Watered barley broth devour, drink warm tar water every hour.

MS: Every hour...

MC: Every...

Bell is heard

MC: Terce, the third Bell, my next appointment. If it remains come back in 4 weeks...
**Part Two: Check Up**

MC: (praying) May the love for my art actuate me at all times, I will respect the secrets which are confided in me, may I see nothing but fellow creatures in pain...

MS: (interrupting) Did you receive my letter Mr. Clarke?

MC: (busy) What? Sit down Miss Sinclair... (diverting subject) How do you feel?

MS: This fever...

MC: Ah yes! Your fever, a rash, on your neck.

MS: Five weeks have passed. I don’t feel any different, in fact I feel another pain.

MC: Let me see your neck! (looks at neck) It’s nothing.

MS: I don’t deserve this - I make such efforts to stay fit, every Sunday.

MC: Instead of worship and rest?

MS: Rest? No, I swear I keep active.

MC: There’s no wonder you are suffering.

MC: Black hats Miss Sinclair, you are paying for your choices, complying with false prophets. Your actions cause your woes Miss Sinclair.
MS: (interrupting) You’re not listening.

INDETERMINATE SECTION 2

MC: Swelling and pain embroiling, Walnuts are good for the head, complaint is the mind’s placebo, black bile rolling, because walnuts look like a head, I’ve no medicine for ego.

MS: My youth would despise me, my job it hurts me, I work so hard, my knee, my rash, my stress, my...

END OF IS2

MC: Hayfever.

MS: Hayfever.

MC: What?

MS: I suffer from hayfever, my brother said my knee pain is just stress. My job it hurts me, my...

MC: (sarcastically) Hayfever and stress. Yes, Miss. Sinclair, I've listened well and you seem fine.

MS: I was just suggesting...

MC: Your trust in found advice divine, summer catarrh and psychosomatics.

MC: (irritated) Mr. Clarke!

MC: (furious) Well why, may I ask, did you seek my advice?

pauses

Stiff upper lip or analyst, I've no medicine for ego.

MS: Mr. Clarke, I was just trying to help.

MC: May your love for my art actuate me at all times, Miss Sinclair, my methods require your faith. Watered Barley broth devour, drink warm tar water every hour.

pauses

MS: Mr. Clarke... Watered Barley broth devour, drink warm tar water every hour.
MC: Every hour.

Miss Sinclair leaves

MC: (laughing it off) Hayfever and stress... (doubting himself) Hayfever... stress...

ENDS
The Birkbeck Pain Project aims to further our understanding of the complex relationship between mind, body and culture by examining narratives of bodily pain produced from the mid-eighteenth century to the present day.

Funded by the Wellcome Trust and based at the Department of History, Classics and Archaeology, this three-year project is led by Professor Joanna Bourke and includes Dr Carmen Mangion and Dr Louise Hide.

We have guest edited 'Perspectives on Pain', a special issue of 19. Interdisciplinary Studies in the Long Nineteenth Century, a peer-reviewed, open-access journal: [www.19.bbk.ac.uk](http://www.19.bbk.ac.uk)

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